

Lisa Freeman

March 17, 2014

To: Representative Susan M. Johnson and other members of the Public Health Committee

My name is Lisa Freeman and I am the very proud parent of a young adult with autism. He is a smart young man with great potential, but he needs support in certain areas that include employment and some skills of daily living – and he needs them today. He needs support so that he can participate in a health way and contribute many wonderful things to his community and his state. He needs support so that he can share his life comfortably with his friends and so that he can find happiness and fulfillment in his own life, as we each seek to do. He needs support so that he can access the personal satisfaction of being able to say, at the end of a day, that whatever he did that day was a job well done!

During the years of public school attendance, our children are entitled to receive certain support services because of the Individuals with Disabilities Education Act (IDEA). The day that they leave the school system by age 22, adult services become almost unavailable, except to the most profoundly impacted by autism. For those who are high functioning and who do not have an intellectual disability, there are few supports – these individuals not only fall through the cracks, they fall into an abyss! The Department of Developmental Services has a program – the Autism Waiver Program – that is set up to provide funding for those individuals with autism who qualify for Medicaid and are not intellectually disabled. But it is minimally funded and right now there are a few hundred qualifying individuals on the wait list and only around 100 receiving services. My own son has been on this list for TWO years and is currently number 68. Who knows how many more years he will remain on the wait list? This is not acceptable!

He is currently working with a counselor at BRS who has paired him with a job coach through BRS. My son and the job coach have been working together to find an appropriate job. But I have been told that my son will need ongoing support for more time than BRS can offer, to maintain a job. BRS does not have the funding for this – they are a short term agency. Apparently they have programs for some clients with funding from other sources. But because my son has been approved for services from DDS through the autism wavier program and does not qualify for services through another agency, and even though HE IS ON A WAIT LIST and receiving NOTHING FROM DDS IN THE MEANTIME, he is not eligible for any of the funding for support that BRS could otherwise offer. The result is that I have been asked to personally guarantee that I will fund ongoing support needed to maintain employment for my son or BRS cannot place him in employment. How unfair is this?

The ironic thing is that if he does enter the workforce and earn salary and pay taxes then he would be needing less of other funding, he would be contributing to the system and he would be living a healthier life, in the broad sense of healthy. How does it make sense, on any level, to underfund support services that save money and lead to less demand on the system in the

end? Are we, through short-sightedness and lack of understanding, contributing to higher system costs for support of co-morbid conditions that could be avoided?

According to the World Health Organization, "Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community. In this positive sense, mental health is the foundation for individual well-being and the effective functioning of a community.... Mental health promotion involves actions to create living conditions and environments that support mental health and allow people to adopt and maintain healthy lifestyles. These include a range of actions to increase the chances of more people experiencing better mental health."

By not funding appropriate support for Persons with Autism Spectrum Disorders we are not giving these residents of Connecticut a chance to experience mental health. Shame on us if we deny these wonderful men and women the funding that they need. This bill needs to be approved.

Respectfully submitted,

Lisa Freeman
(Parent of a young adult who is autistic)
65 Mayweed Road
Fairfield, CT 06824